

Healing the psychological stress in NICU



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Our Team

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Aims

- Our work – types of referral
- Sources of parent psychological distress in NICU
- Evidence base
- Interventions
- Thoughts for the future

Roles – support and input for:

- Parent mental health
- Parent-infant relationship
- Staff working with stressed families

“Please see this family for support in their journey through NICU”

- Miles (1989) identified 4 specific aspects of NICU with potential to be highly stressful:
 1. NICU physical environment
 2. Infants physical appearance and behaviour
 3. Staff and parent interactions
 4. Alteration in the parental role

Parents speak ..

- “... I mean it was like our own child, but we didn’t know what we could do with her. Its kind of a strange feeling where she’s yours but you have to ask permission to do things” (from Kenner & McGrath, 2004)
- “Imagine the nurse pulls back the Saran Wrap for you to touch him, and you just can’t bring yourself to do this, for your finger is longer and thicker than his arm, and his hand is only the size of your fingertip” (from Maroney, 2004)

Metaphors for the journey

Aagard and Hall (2008)

- “From their baby to my baby” (acquiring more control of the parental role)
- “striving to be a real, normal mother”
- Environmental influences “from the foreground to the background”
- Role evolution “from silent vigilance to advocacy”
- Relationship with staff “from continuously answering questions to sharing knowledge”

Common themes in parents experiences of NICU

- Trauma of pre-term birth “shell-shocked”
- Fear of infant death
- Guilt /shame
- Coping with the NICU environment
- Coping away from home and supports
- Mothers own medical needs – ‘falling through the gaps’
- What is expected of me?
- Grief re diagnosis, loss of twin, normal pregnancy experiences

Common themes ...

- Anger and mistrust secondary to perinatal experiences
- Understanding medical information and who to listen to (including seeking outside information)
- Parent roles “who does this baby ‘belong’ to?”, am I good enough? How can I be a parent in NICU?
- Separation from baby “is this nurse a safe pair of hands?”
- Milk supply

Common themes for parents in NICU

- Transition level 3 to 2 often hard
- Helping siblings cope
- “Why is this parent not coming in ?” Resources, ? Avoidance (coping style or PTSD), ? Mental health issues, ? Cultural, ? Attachment history ? Disempowered/role adjustment
- Stress associated with the ‘long haul’
- Often increased anxiety in PIN

An initial approach to parents

- “Meet and greet” introduction to service vs. in depth interview
- Acknowledge and normalise stressors
- Understanding their personal situation
- Acknowledge their role as parents, explore positives and difficulties
- Meet their infant and ask what they have learned about her medical condition or him as an individual
- Ask about relationships with staff, preferences re information

Approach to parents ...

- Ask about physical state
- Ask about social supports
- Ask about usual coping strategies
- Brief screen for mental health issues
- Discussion regarding self-care, help with problem-solving, permission to discuss fears and “dark feelings”, relaxation skills, couple work, advice re siblings

Parental vulnerabilities

- Parental mental health
 - Impact on capacity to relate to infant and to staff
 - Difficulty accessing services
- Cultural misunderstandings
 - hospitals largely run and staffed by Pakeha
 - Assumptions re family roles, childcare practice
- Previous history of trauma and loss
 - Pregnancy loss, IVF
 - Previous experiences in the hospital system
 - Own hx of abuse and disrupted attachment
- Domestic/family violence
 - Care and protection issues, difficulties achieving a therapeutic focus and service coordination



Issues for staff

- Balancing of roles, expertise and control
- Technological and procedural imperatives
 - Easier to measure/operationalise instrumental care
- Communication skills and challenges
 - managing communication difficulties, breaking bad news
- Personal discomfort with parents/families from different cultures who hold different values and priorities
- Stress of close contact with anxious, distressed, unwell or angry family for 12 hours at a stretch
- Vicarious trauma

“we are concerned about the staff-family relationship” – parent factors

- Acute stress – fight-flight-freeze
- Loss of control
- Vigilance/ “watching over” – being alert to indications of safety and wary of circumstances signaling danger for baby in NICU
- Personality styles and premorbid difficulties with emotional regulation
- Difficulties with trust and/or adverse past or perinatal healthcare experiences
- Projection
- Information processing – stress, mental illness, ASD

“ We are concerned about parents mental health”

- Pre-existing illness – liaison role with MMH, adult MH
- Depression and anxiety – increased incidence in parents of premature/LBW infants at least in first 12 weeks. May be as high as 40% (systematic review, Vigod et al 2009)
- Christchurch NICU (Carter, Mulder and Bartram, 2007) 22% clinically significant depression and 18% clinically significant anxiety (controls 12% and 7%) Increased anxiety and depression no longer present by 9 months

Parental Mental Health

- Vigod et al – Mothers of very premature/VLBW babies consistently demonstrated to have higher levels of depressive symptoms through first year.
- Ongoing infant illness, low social support risk factors
- PTSD – increased at 2-3 years particularly in the VLBW group

“ we (or the parent) are concerned about the parent-infant relationship

- Prematurity per se doesn't confer added risk of insecure attachment
- Risk **may** be increased for infants with neurological damage or high medical risk
- Parents may worry about ability to bond with infant
- VLBW infants very different to a term baby as a 'social partner'
- Premature infants may have difficult to read cues, less mature regulation
- High parental anxiety or depression can affect sensitive responding

High risk families

- Distorted representation of the infant
- Parental preoccupation with past trauma
- Deficits in interpretation of infants emotional communication
- Limited reflective capacity
- Observations: non-contingent responses, role confusion, negative-intrusive behaviour, frightening/frightened behaviour
- These predict infant disorganised attachment
- Usually indicate personality disorder or severe trauma history in parent

Interventions

- Providing a therapeutic relationship
- Containment of distress
- Liaison with Child Protection and other child agencies
- Referral to Adult Mental Health
- Referral to Infant Mental Health

Other areas of involvement

- Distressing news meetings
- Antenatal involvement
- Bereavement
- After transfer to Starship
- Education
- Supervision/debriefing

The future

- Formal psychosocial assessments
- Written resources for parents
- ? More formalised program e.g. COPE/NICU (Melnik & Feinstein, 2008)
- Improving links with other agencies
- Ongoing progress toward family-centered care – sibling playroom, places to rest for parents.

The Healing Relationship

“any relationship that enhances the process of recovery, repair and return to wholeness through characteristics such as communication, caring, compassion, empathy, rapport and support”

Samueli Institute, 2002